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## Primary Care for Adults on the Autism Spectrum

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Autism spectrum disorders; Primary care; Adults; Developmental disabilities

## INTRODUCTION

Although autism was once considered rare, it is now estimated that 1% of adults meet current criteria for autism spectrum disorder (ASD) with no difference in prevalence by age.<sup>1</sup> Because of changes in diagnostic criteria and their application over time, fewer adults have been formally diagnosed, but the large cohort of children diagnosed with ASD in the past 2 decades is rapidly approaching adulthood.

Autism, like other disabilities, does not preclude one from being healthy. However, cognitive and communication differences can complicate identification and management of illnesses unrelated to the disability. Also, autism is associated with increased prevalence of several medical conditions. The clinician's role is to prevent and treat illness, while providing support and accommodations for the disability. This article focuses on the identification of ASD in adults, potential referrals for services, the recognition of associated conditions, strategies, and accommodations to facilitate effective primary care services for autistic adults, and ethical issues related to caring for autistic adults. (Of note, we use terms such as "autistic adults" in this paper to respect the Autistic self-advocacy community's preference for identify first language over person-first language.)

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As the literature on ASD in adults is at times sparse, we supplement existing evidence with recommendations from our professional and personal experiences as primary care physicians (PCPs), researchers, parents, and patients. Many of our recommendations arise from our National Institute of Mental Health–funded project with the Academic Autism Spectrum Partnership in Research and Education (AASPIRE, [www.aaspire.org](http://www.aaspire.org))<sup>2</sup> to develop a health care tool kit for autistic adults, their supporters, and their PCPs (<http://autismandhealth.org>), as well as from our work with the Office of Developmental Primary Care (<http://ODPC.ucsf.edu>).

We also extrapolate information from the body of literature on intellectual disability, although this extrapolation poses limitations. Some autistic individuals have intellectual disabilities. Others do not. Clinical data and strategies for people with intellectual disability are sometimes, but not always, applicable to people on the autism spectrum. Some notable differences are that autistic adults are more likely to struggle with communication pragmatics (eg, interpreting ambiguity or nuance, understanding context), have a higher level of education, and be impacted by atypical sensory experiences, and they are less likely to have a support system through county or state disability services. In general, clinicians should tailor their approach to the individual's needs, regardless of the patient's diagnostic label.

## ASD DIAGNOSIS IN ADULTS

In 2013, the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) unified autistic disorder, Asperger's disorder, childhood disintegrative disorder, and Pervasive Disorder Not Otherwise Specified into one diagnosis called ASD.<sup>3</sup> Although the DSM-5 conceptualizes ASD primarily as a social-communication disorder, there is also a growing literature supporting the hypothesis that ASD may be primarily characterized by differences in information processing.<sup>4</sup>

A large number of today's autistic adults may not have been formally diagnosed and/or may have been misdiagnosed with other conditions. PCPs may recognize characteristics of ASD in undiagnosed patients or in patients with other diagnoses. Patients also may diagnose themselves and offer this information to facilitate care or seek formal diagnosis. Recognition of ASD in adults can be challenging. Like people without disabilities, autistic individuals change and mature with age, and may develop coping strategies and skills that make autistic traits less noticeable. Furthermore, diagnostic criteria can manifest in multiple ways (see Table 1). For example, the DSM-5 criterion of "impaired social communication" may be met by someone with no speech or by someone with fluent speech and difficulty interpreting nonverbal cues.

Although ASD is referred to as a "spectrum" disorder, individuals do not fall on one linear spectrum of "low" and "high" functioning.<sup>5</sup> Instead, skills or challenges fall along spectra on multiple axes (spoken language, written communication, activities of daily living, need for consistency, sensory sensitivity, emotional regulation, and so forth). A patient with no spoken language may be able to read and write at a graduate level and an individual who

speaks fluently may have profound learning disabilities. Within each axis, skills and challenges can change depending on environmental stimuli, supports, and stressors.

When considering a diagnosis, it is important not to rely on stereotypes. Autistic traits can be both strengths and challenges. Some autistic individuals develop great expertise in their areas of special interests, or capitalize on their need for consistency to self-manage chronic conditions. On the other hand, not all autistic individuals have stereotypically positive traits, such as memorization or computation, or possess savant skills. Autistic people do not always shy from social interactions, and many maintain strong friendships or relationships. Although, on average, autistic individuals have lower scores on tests of “cognitive empathy” (understanding another person’s perspective) than nonautistic individuals, many score in the normal range. Moreover, autism is likely not associated with limitations in “affective empathy” (an observer’s emotional response to the affective state of others).<sup>6</sup>

Clinicians should discuss risks and benefits of referral for formal diagnosis (Box 1). Referral can be challenging, as many autism specialists lack experience with adults. Diagnostic evaluation should draw on a variety of sources, including standardized diagnostic instruments such as the Autism Diagnostic Observation Schedule (ADOS).<sup>7</sup>

#### **Box 1**

##### **Potential risks and benefits of obtaining autism spectrum disorder (ASD) diagnosis in adult patients**

Potential benefits of a formal diagnosis are as follows.

- Would confer anti-discrimination and legal rights to accommodations in school, at work, in health care, or in other settings.
- May assist the individual in developing a better understanding of self.
- May provide peace of mind through the professional confirmation of life experiences.
- May provide means to experience better coping or quality of life by more directly recognizing strengths and accommodating challenges.
- May provide other means to understand and support the individual.
- May qualify the individual for benefits and services for people who have an ASD diagnosis.
- May qualify the individual for programs for people with disabilities, such as scholarships or incentives that are meant to increase workplace diversity.

Potential risks associated with seeking an ASD diagnosis are as follows.

- The process of seeking and being evaluated for the diagnosis may be stressful.
- The person may perceive the interaction with the diagnostician or provider as negative, disrespectful, or otherwise uncomfortable.

- The interpretation of ASD criteria and subsequent diagnosis varies by provider, particularly in the adult presentation.
- Information about an individual's ASD could potentially negatively impact child custody cases.
- Others in the individual's life may still not be supportive, even with the diagnosis.

*Adapted from the Academic Autistic Spectrum Partnership Research and Education (AASPIRE) Healthcare Toolkit. Available at: <http://autismandhealth.org/>. Accessed June 23, 2014.*

## REFERRALS FOR ASSISTIVE TECHNOLOGIES AND THERAPIES

Assistive technologies, therapies, and services for autistic adults are not meant to treat or cure autism. They may improve function or quality of life by increasing coping strategies, treating co-occurring conditions, or providing access to accommodations and supports. Patients should select therapeutic goals and choose whether they wish to participate in therapy.

Assistive and augmentative communication (AAC) technology can improve communication for adults with limited or variable speech. AAC includes tools such as letter or picture boards or devices that translate text into speech. Adults can benefit even if such technology was not introduced in childhood. Sometimes patients' intellectual capabilities were underestimated, or the technology was not available. In other cases, patients develop the skills to use these technologies later in life. Some patients with fluent speech may lose their ability to speak when stressed or overwhelmed and can benefit from using AAC intermittently. Others may simply communicate more effectively using AAC. Previous failed attempts to use AAC, or the presence of speech, should not preclude consideration of an AAC referral. See Table 2 for examples of AAC technology. Other assistive technologies that may be useful include speech-to-text (eg, Dragon Naturally Speaking) or word-completion programs, electronic or paper organizers, or visual or electronic reminders and alarms to help with prompting or sequencing. Consider offering referrals to speech and language pathologists or occupational therapists to address communication challenges or difficulty managing activities of daily living.

Depression, anxiety, posttraumatic stress disorder, and other mental health conditions may be more prevalent in autistic individuals;<sup>8,9</sup> however, mental health conditions are not inherent to autism. Mental health therapy may be useful to develop strategies for communication, organization, or sensory sensitivities, or to learn ways to understand and manage social situations and change. Therapy may be helpful to understanding and responding to negative emotions or preventing melt-downs. However, it may be necessary to find a therapist with experience working with autistic patients. Because of the socio-communication differences inherent in autism, assumptions about how to communicate with patients, understand patient behavior, or foster therapeutic relationships may not apply.

Local autism centers, autism organizations, developmental disability programs, or professional organizations may have names of therapists with expertise working with autistic adults, or may be able to offer supports and services directly. Vocational rehabilitation services may be able to help patients obtain or sustain employment, including by assisting with referrals to therapists. Box 2 lists potential resources.

## Box 2

### Resources for autistic patients, families, and health care providers

#### Resources for Primary Care Providers

- *Academic Autism Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit*. Targeted to autistic adults, supporters, and primary care providers. Includes the Autism Healthcare Accommodations Tool (AHAT), worksheets and checklists, and step-by-step guides: [www.autismandhealth.org](http://www.autismandhealth.org).
- *University of California San Francisco Office of Developmental Primary Care*. Resources about developmental disabilities for primary care providers, including forms for behavior assessment: <http://odpc.ucsf.edu/>
- *Health Care for Adults with Intellectual and Developmental Disabilities*. Toolkit for Primary Care Providers: <http://vkc.mc.vanderbilt.edu/etoolkit/>

#### Information on Autism-Related Services and Resources

- *Autism NOW Center*. National Autism Resource and Information Center, sponsored by the Administration on Intellectual and Developmental Disabilities (AIDD): [www.autismnow.org](http://www.autismnow.org)
- US Department of Health and Human Services *Administration for Community Living* maintains a comprehensive list of relevant agencies and resources: [http://www.acl.gov/Get\\_Help/Help\\_Indiv\\_Disabilities/](http://www.acl.gov/Get_Help/Help_Indiv_Disabilities/)
- *Autism Society of America*: <http://www.autism-society.org/>

#### The Americans with Disabilities Act (ADA) in health care

- Main ADA page: <http://www.ada.gov>
- For more information on the ADA and health care: <http://www.pacer.org/publications/adaqa/health.asp>
- For an in-depth legal analysis of the ADA in health care, see <http://www.ncbi.nlm.nih.gov/books/NBK11429/>
- ADA Centers see <http://adata.org/Static/Home.html>
- ADAdata.org has a frequently asked questions page where you can learn more about the ADA: <http://adata.org/faq-page>
- The Autistic Self Advocacy Network has a series of policy briefs on health care and intellectual and developmental disabilities: <http://autisticadvocacy.org/>

#### Autistic Community Links for Patients

Books and Guides for Autistic Individuals from the Autistic Self-Advocacy Network (available at <http://autisticadvocacy.org/about-asan/books/>) include the following:

- Welcome To The Autistic Community: <http://autisticadvocacy.org/wp-content/uploads/2014/02/WTTAC-Adult-FINAL-2.pdf>
- Navigating College: <http://navigatingcollege.org/>
- Loud Hands: Autistic People, Speaking (ISBN-10: 1938800028)

Autistic Advocacy Groups and Forums

- The Autistic Self-Advocacy Network: <http://autisticadvocacy.org/>
- Autism Women's Network (AWN): <http://autismwomensnetwork.org/>
- Wrong Planet: largest online autistic forum with more than 80,000 members. WrongPlanet.net
- The Thinking Person's Guide to Autism: <http://www.thinkingautismguide.com/>
- Autism National Committee: <http://www.autcom.org/>

## ASSOCIATED CONDITIONS

Both genetic and environmental factors play a role in health outcomes.<sup>10</sup> Current evidence suggests autistic adults have high rates of associated chronic medical illness, especially epilepsy, gastrointestinal disorders, feeding and nutritional problems, metabolic syndrome, anxiety, depression, and sleep disturbances. Iatrogenic problems, such as side effects of medications, are also common,<sup>11,12</sup> as is exposure to violence and abuse.<sup>13</sup>

### Mortality

There is some evidence that autism is associated with modestly reduced life expectancy. The expected number of deaths is approximately 2 to 3 times higher than age-matched and sex-matched peers in the general population.<sup>14</sup> Risk factors include moderate to severe intellectual disability, epilepsy, and female sex. Death from seizures, sudden unexpected death in epilepsy, and accidents, such as suffocation and drowning, are more common, but there is also increased risk of mortality from a wide variety of causes that also are found at similar rates in the general population. The excess mortality from these causes might reflect difficulties in recognizing and reporting signs and symptoms or in accessing health care.<sup>14–17</sup>

### Epilepsy

Approximately 20% to 30% of autistic adults have co-occurring epilepsy. The first seizure often occurs during adolescence. Autistic adults with intellectual disability have higher rates of epilepsy than those with normal intelligence.<sup>14,18</sup> Epilepsy can be misdiagnosed due to misinterpreting events as behavioral tics, lack of attention, emotional outbursts, stereotyped movements, or other presentations.<sup>19</sup> On the other hand, calming repetitive movements, atypical facial expressions, or unusual behaviors can be confused with seizure spells. Seizures can be missed more easily in patients who have nontraditional ways of



communicating or who have complex teams providing their support.<sup>20</sup> Caregiver education and capturing spells on video can aid accurate diagnosis. Clinicians also should monitor side effects of antiepileptic medications and do regular pharmacy reviews for drug interactions. Antiepileptics are a risk factor for osteoporosis and vitamin D deficiency.<sup>21</sup> Consider side effects of anti-seizure medication in the differential diagnosis of a change in behavior.

### **Gastrointestinal Disorders**

Gastrointestinal disorders, such as gastroesophageal reflux, constipation, and food intolerances are commonly reported by autistic people.<sup>22</sup> However, the prevalence, etiology, and treatments for these conditions are not well studied.<sup>23</sup> Physical distress from gastrointestinal problems can increase agitation. Identifying and treating gastrointestinal problems may reduce what appear to be symptoms of psychiatric illness. Dysphagia and esophageal reflux are common in people who have difficulty producing clear speech. Consider a swallow study in patients who cough or become short of breath with meals.

### **Feeding and Nutrition**

Feeding problems and poor nutrition can result from unrecognized reflux, constipation, bowel motility problems, dysphagia, or dental problems. Feeding and nutritional issues also can be related to sensory sensitivities to flavors, textures, or smells. Some autistic patients may have difficulty identifying the sensation of hunger, managing cooking or the grocery store, or initiating the actions required to prepare or consume meals; these individuals may require prompts and support. Sometimes autistic people have not been offered basic education about healthy lifestyles in a format they can understand. Our tool kit includes a variety of accessible patient materials about nutrition and exercise (<http://autismandhealth.org>). Clinicians can encourage supporters and programs to facilitate healthy eating and exercise habits, and to avoid using foods as rewards.<sup>24</sup>

### **Metabolic Syndrome**

Based on retrospective chart reviews, autistic adults appear to have a higher-than-average prevalence of hypertension, hyperlipidemia, obesity, and diabetes.<sup>11,12</sup> Clinicians should perform age-appropriate screening of weight, blood pressure, cholesterol, and blood sugar, minimize the use of medications, such as antipsychotics, that are known to exacerbate metabolic syndrome, and provide accessible information about lifestyle modifications.

### **Mental Health**

A systematic review of 40 studies found high rates of anxiety in autistic children and adolescents.<sup>8</sup> One study of anxiety across the life span in autistic individuals found that anxiety rises from toddlerhood to childhood, decreases from childhood to young adulthood, but again increases from young adulthood into older adulthood.<sup>25</sup> There is also growing evidence that autistic individuals experience high rates of depressive illnesses.<sup>9</sup> Behavioral and psychiatric disorders in people with developmental disabilities are often the result of social and physical stressors, trauma, discrimination, and lack of effective communication. Some of the excess frequency of psychiatric illness may be preventable.<sup>26</sup> Mainstream



mental health and disability support services often have inadequate training to work with autistic adults.<sup>27</sup> Referral to regional subspecialty services may be required.<sup>28</sup>

Psychiatric diagnoses can be made in people with intellectual disabilities or who communicate in nontraditional ways. The National Association for the Dually Diagnosed has published an adaptation of the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* for intellectual disability,<sup>29</sup> although one does not yet exist specific to autism. Once a diagnosis is made, careful therapeutic trials of standard medications and treatments are reasonable.

### Sleep Disturbances

Sleep disturbances are commonly reported both in autistic children<sup>30</sup> and adults.<sup>31</sup> Longitudinal studies show sleep problems persist as children age.<sup>32</sup> Sleep problems are associated with challenging behavior, respiratory disease, visual impairment, psychiatric conditions, and may be exacerbated by medications, especially psychotropic, antiepileptic, and antidepressant medications.<sup>33</sup> Patients should be assessed for possible medical problems, such as esophagitis or unrecognized pain.

Melatonin has the best evidence to support its effectiveness in autistic people and has a favorable side-effect profile. Patients can try 1 to 10 mg orally 30 minutes before bedtime.<sup>34,35</sup> Nonpharmacological approaches, such as sleep hygiene, also may be effective.<sup>36</sup>

### Violence and Abuse

There is strong evidence to suggest both men and women with disabilities are more likely to experience violence victimization than the general population.<sup>13</sup> People with disabilities are at risk for physical and sexual violence from intimate partners, caregivers, and peers. Abuse also can take the form of refusal to provide assistance with essential activities of daily life, economic abuse, and the withholding of an assistive device. Clinicians should regularly screen for violence and should always keep violence or abuse in the differential diagnosis for injuries, changes in behavior, worsened mental health issues, or unexplained medical problems.

## FACILITATING EFFECTIVE HEALTH CARE INTERACTIONS

People with disabilities face significant disparities in health and health care.<sup>37–39</sup> We have found that autistic adults experience greater unmet health care needs, greater emergency room use, less use of recommended preventive care services, lower satisfaction with health care, lower health care self-efficacy, and a greater number of barriers to health care than nonautistic adults.<sup>40</sup>

Many ASD characteristics can directly impact health care. Effective physician-patient communication correlates with improved patient health outcomes, even in general populations.<sup>41</sup> In our qualitative study, autistic adults described examples of how failure to accommodate communication, sensory integration, and executive functioning resulted in poor outcomes. They also reported that their uneven skills<sup>42,43</sup> led providers to make false

assumptions about their abilities to understand health care issues, communicate, or navigate the health care system.<sup>44</sup>

Table 3 lists ASD-related characteristics that can impact health care interactions, with recommendations for strategies or accommodations. Box 3 offers additional strategies and accommodations for facilitating physical examinations, tests, procedures, phlebotomy, and dentistry. As each patient is unique, it is important to understand his or her individualized needs and preferences. AASPIRE has created the Autism Healthcare Accommodations Tool (AHAT), an interactive tool for patients and supporters to create a provider-friendly report of individualized strategies and accommodations to facilitate health care; it can be accessed at <http://autismandhealth.org>.

### Box 3

#### **Strategies and accommodations for successful physical examinations, tests, procedures, phlebotomy, and dentistry**

##### **Physical examinations, tests, and procedures<sup>a</sup>**

The following are examples of accommodations or strategies that may help some patients:

- Explain what is going to be done before doing it.
- Show the patient equipment (or pictures of the equipment) before using it.
- If possible, let the patient do a “trial run” of difficult examinations or procedures.
- Tell the patient how long an examination or procedure is likely to take.
- Warn the patient before touching or doing something to him or her.
- Limit the amount of time a patient has to be undressed or in a gown.
- Give patients extra time to process things they need to see, hear, or feel before they respond.
- Allow the patient to sit, lie down, or lean on something during procedures, when possible.
- Let patients use a signal to tell you they need a break.
- Ask the patient from time to time if he or she is able to handle the pain or discomfort.

In many cases, thoughtful planning and appropriate accommodations can enable patients to tolerate examinations and procedures that have previously been intolerable. Still, there may be times when patients need anesthesia to tolerate examinations or procedures.

<sup>a</sup>Adapted from the Academic Autistic Spectrum Partnership Research and Education (AASPIRE) Healthcare Toolkit. Available at: <http://autismandhealth.org/>. Accessed June 23, 2014.

*Phlebotomy*<sup>a</sup> may be particularly challenging for some (but not all) patients on the autism spectrum. If a patient has had a particularly hard time with blood draws, you may consider some of the following strategies and accommodations:

- Only order blood tests when absolutely necessary and group them together to minimize the number of draws.
- Allow the patient to lie down or lean back on something.
- Use a numbing spray or cream.
- Be very patient and use a calm voice.
- Give the patient a very detailed explanation of what will happen, including how many tubes of blood you will fill.
- Consider giving the patient an anti-anxiety medication before the blood draw.
- Give the patient a lot of advance warning so he or she can prepare himself or herself emotionally.
- Give the patient something to distract his or her attention.

*Dentistry* may require additional accommodations to reduce barriers to accessing care. The following strategies may be useful to some patients.

- To accommodate sensory issues
  - Noise-reducing ear phones
  - Dark glasses or an eye pillow
  - Use of a private room or scheduling as the last of the appointment of the day to reduce or eliminate noise from other patients
- To tolerate examinations, cleanings, or procedures
  - Use of nitrous oxide during the visit
  - Use of valium or other sedative before the visit
  - Anesthesia
- To accommodate other stressors
  - Providing clear indication of the order of events
  - Indicating how long each event is likely to take
  - Decreasing wait time
  - Minimizing small talk and other distractions
- To accommodate challenges with dental hygiene
  - Adaptive toothbrushes
  - Water pic and suction
  - Chlorhexidine oral rinse on a swab or brush

- Use of xylitol sprays or chewing gum
- Increasing time between meals
- Use of mouth rinse or baking soda in water

When caring for autistic adults, obtain information about their communication, including speaking and understanding spoken language, reading and writing, use of AAC, and effects of stress on communication. Attempt to use the most effective communication mode for the patient, even if it means altering your usual interview style. Also note that many patients cannot effectively communicate via telephone, even if they speak fluently, and need to establish alternate ways to communicate between visits.

Figures of speech, vague statements, and broad questions can be problematic for individuals who take language literally or who require very precise language. Patients may experience anxiety if they cannot answer a question with 100% accuracy. It is best to be concrete and specific. Some patients may be able to respond to questions better if offered multiple-choice-style answers, examples of the types of things people may experience, or are reassured that they do not need to be 100% accurate.

Patients may have difficulty understanding nonverbal cues and may inadvertently seem rude because of their atypical body language or facial expressions. Do not force a patient to make eye contact, as it may cause discomfort or hamper his or her ability to communicate.

Autistic individuals may have difficulty processing information quickly enough to respond to questions or make health care decisions in real time. For example, patients report insufficient time to indicate that an area is tender before the provider begins palpating a different area. Give patients time to process information or stimuli, and check for understanding before moving on. Encourage patients to prepare information before the visit and try to write down key information so that they can review it later. It may be necessary to schedule longer appointments or a second visit.

Autistic individuals commonly have atypical sensory processing, including increased or decreased sensitivity to sounds, lights, smells, touch, or taste. They may have great difficulty filtering background noise, processing information in overstimulating environments, or processing more than one sensation at a time. Sensory issues can compromise a patient's ability to communicate or tolerate a health care visit. It is important to assess a patient's sensory needs and find ways to remove environmental barriers to care. Repetitive behaviors ("stimming") may be an effective coping mechanism, especially during times of stress. Do not dissuade stimming behaviors or assume that a patient is not paying attention because of fidgeting, repetitive movements, or lack of eye contact.

Autistic patients may experience challenges related to limited body awareness. Examples include difficulty discriminating abnormal from normal body sensations, difficulty pinpointing the location of a symptom, difficulty characterizing the quality of a sensation, experiencing particularly high or low pain thresholds, displaying atypical body language when in distress, and difficulty recognizing normal stimuli such as hunger or the need to micturate. It is important to ask the patient about differences in body awareness that may

affect recognition or description of symptoms, or responses to pain or illness. In some cases, you may need to do additional testing or imaging.

Autistic individuals often require great consistency. Changes in routine can provoke confusion or anxiety, leading to melt-downs or an inability to function. They may need clear agendas and more detailed explanations than other patients to plan for a visit or to stay focused and comfortable, or may benefit from trial runs for difficult procedures. Other autism-related factors that can affect health care interactions include limited time awareness, or difficulties with planning, organization, and sequencing.

Some autistic adults have difficulty accessing dental care because of sensory challenges, financial barriers, and a lack of qualified clinicians. Strategies include providing information on what to expect for how long, decreasing wait times, and minimizing small talk and other distractions, as well as sensory accommodations, such as seeing the patient in a private room where the sounds of concurrent dental work are reduced. Creative collaboration with patients and supporters can help reduce the need for dental care under sedation or anesthesia. However, some patients require the use of agents such as nitrous oxide or referral to hospital dentistry.<sup>23,45</sup>

Barriers to care may be more or less prominent depending on environmental factors, illness, and the supports available to a patient. It is important to work with patients and their supporters to determine useful strategies and accommodations. If possible, discuss strategies during routine visits, as they are often most needed during times of crisis when it is hardest to develop them de novo.

## UNDERSTANDING AND ADDRESSING BEHAVIOR CHANGE

In people with nontraditional communication or atypical cognition, common medical problems can present in unusual ways. Illness often presents as a change from baseline behavior or function. For example, pain can present as social withdrawal or self-injurious or agitated behavior. If the behavior or illness makes caregiving easier (eg, amenorrhea or decreased activity levels) caregivers often fail to report the change. Therefore it is important to record the patient's baseline in the areas of cognition, mental health/behavior, fine and gross motor function, sensory integration and function, and seizure threshold.

Patients may not reliably volunteer information or may describe their symptoms in atypical ways. Caregivers also may not volunteer information, may misinterpret behavior, or have competing interests. Clinicians should always attempt to obtain a history directly from their patient. However, when needed, with permission, caregivers and supporters can be important supplementary sources of information.

### Challenging Behavior

Challenging behavior is usually not a presenting complaint from a patient. Caregivers seek consultation because they feel challenged. As a first step, it is important to determine if the stress is due to a change in the function or behavior of the patient, or from a change in the

caregiver's resiliency or ability to provide support. The solution may include helping the caregiver with additional supports, training, or relief from caregiving responsibilities.

Typically, caregivers are focused on stopping the target behavior. Determining the cause can take time and additional work when a caregiver is already overwhelmed. But understanding the cause of the behavior is critical. Start by asking the patient, even if the patient does not communicate in traditional ways. Remind caregivers that all behavior is a form of communication and that all people communicate. Clinicians should consider a full differential diagnosis, including common medical and psychosocial causes (Boxes 4 and 5). Psychiatric illness is only one possible cause of aggression or challenging behavior. Patients who present to specialty psychiatry services frequently have undiagnosed or undertreated medical problems contributing to their condition.

**Box 4****Common medical causes of a change in behavior or function**

- Constipation
- Dental problems
- Dysphagia
- Esophageal reflux
- Headaches
- Hearing changes
- Hypothyroidism
- Kidney stones
- Seizures
- Side effects of medications
- Trauma
- Urinary obstruction or retention or new incontinence
- Urinary tract infections
- Vision changes

**Box 5****Common psychosocial causes of a change in behavior or function**

- Abuse or neglect
- Caregiver stress causing a change in support
- Escape or avoidance of demands
- Increase or decrease arousal

Means to access an activity or object

Mental illness

Need for attention

Pursuit of control and autonomy

Reduction of anxiety

Substance use or abuse

### Pharmacologic and Nonpharmacologic Approaches to Challenging Behavior

The primary treatment for challenging behavior is to diagnose and address the underlying cause. However, the cause may not be readily apparent. Both pharmacologic and nonpharmacological approaches may need to be explored.

Although short-term use of risperidone or aripiprazole has been shown to be effective in treating irritability, hyperactivity, and stereotypies in autistic children, the risks and side effects often outweigh the benefits.<sup>46</sup> There are no data regarding the benefit of long-term antipsychotic medication in autistic individuals.<sup>47–49</sup> People with intellectual and developmental disabilities have high rates of complications from long-term use of antipsychotic medication, such as movement disorders, obesity, hyperprolactinemia, and metabolic syndrome.<sup>50,51</sup> In children, increased risk of diabetes is apparent within the first year of treatment with antipsychotic drugs, including newer atypical medications, and the risk increases with total cumulative dose.<sup>52,53</sup> Even after long-term use, discontinuing antipsychotic medication improves metabolic parameters. For antipsychotics prescribed for challenging behavior in adults with intellectual disability, discontinuing them is associated with improved behavioral function.<sup>54</sup> Although autism-specific data are not available, studies suggest that the use of antipsychotic medication is not cost-effective for adults with intellectual disability. Despite weak evidence to support the practice, long-term antipsychotic medications are frequently prescribed for autistic individuals. Before selecting a treatment, patients and caregivers should know that aggressive behavior frequently remits over the short-to-medium term.<sup>48,55</sup>

There are some data to support the efficacy of nonpharmacological treatment approaches. Mindfulness interventions are effective to reduce behavioral and psychological problems in people with developmental disabilities, including autism.<sup>56–58</sup> Cognitive behavioral therapy for anxiety also is effective in autistic people.<sup>59</sup> Physical exercise has been shown to reduce stereotypy, aggression, off-task behavior, and elopement in autistic people.<sup>60</sup> Functional assessment and improved communication have also been shown to reduce challenging behaviors.<sup>61,62</sup>



## LEGAL AND ETHICAL CONSIDERATIONS

### Decision-Making Capacity; Surrogate Decision Makers

Issues of autonomy can be particularly significant for autistic individuals, many of whom have been denied opportunities for self-determination. The capacity of autistic people to consent to treatment or participate in shared decision-making is often overlooked. With appropriate accommodations, people with communication or intellectual disabilities can usually understand the options, weigh the risks and benefits, and communicate a choice. Some medical decisions are more abstract than others, so capacity to make an informed decision should be assessed separately for each decision.

People who lack capacity to make a specific decision independently often can decide who they trust to support them in decision-making and complete a Power of Attorney form. Others may be able to contribute information about their values and priorities for consideration.

Clinicians, caregivers, family members, and case managers all have competing interests that need to be managed. One technique for managing this is to list and distinguish what is important to and for each team member (Box 6).

#### Box 6

##### Example of strategy listing what is important to and for patient and team members as a way to manage competing interests

Important *to* the patient: Avoid the pain of a needle stick.

Important *for* the patient: Get laboratory tests drawn.

Important *to* the caregiver: That she be the one to provide support.

Important *for* caregiver: End clinic visit to get to work on time.

Solution: Provider writes prescription for numbing cream to be applied 1 hour before a laboratory appointment on a convenient date.

Some autistic adults have a conservator or guardian. When surrogates support a patient, they should be encouraged to solicit the patient's values and priorities. If it is impossible, even with supports, to include the patient in any way, surrogates should be encouraged to base their decision on their best estimate of what the patient would choose if he or she was able to be involved, rather than on what the surrogates prefer.

### Access to Care

Access to health care is a civil right under the Americans with Disabilities Act (ADA). The ADA does not list specific recommendations but instead requires individualized strategies to address the specific barriers posed by an individual's impairments. It is the responsibility of clinicians and health plans to provide access to care for people with disabilities. Examples include large print, translators, plain language, or visual presentations; sensory accommodations such as quiet rooms and dimmed lights; and longer appointment times. The

act of requesting accommodations can in and of itself be challenging for autistic individuals who struggle with social communication. Our AHAT can help patients create personalized accommodations reports for health care providers. Taking the time to respond to accommodation requests can ultimately save time, improve the therapeutic relationship, and facilitate effective care.

## SUMMARY

Clinicians can work with patients on the autism spectrum and their supporters to find effective strategies and accommodations to reduce barriers to care. In people with nontraditional communication or atypical cognition, illness often presents as a change from baseline behavior or function. Clinicians should consider a full differential diagnosis, including common medical and psychosocial causes. Appropriate supports and accommodations can reduce illness and disability and maximize patient autonomy and quality of life.

### KEY POINTS

- The autistic population is very heterogeneous; individuals' skills or challenges fall along spectra on multiple axes (spoken language, written communication, ability to perform activities of daily living, need for consistency, sensory sensitivity, emotional regulation, and so forth) and can change depending on environmental stimuli, supports, and stressors.
- Autistic adults have increased rates of chronic medical illnesses, including epilepsy, gastrointestinal disorders, feeding and nutritional problems, metabolic syndrome, anxiety, depression, and sleep disturbances, and greater exposure to violence and abuse.
- Clinicians may improve quality of life by recommending accommodations, assistive technologies, therapies to improve adaptive function or communication, and caregiver training, and by supporting acceptance, access, and inclusion.
- Access to health care can be improved by using alternative communication strategies, reducing sensory stimuli, providing additional structure to visits, allowing extra time, and using visual aids.
- Illness often presents as a change from baseline behavior or function. When patients present with behavioral concerns, clinicians should consider medical and psychosocial causes.

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Table 1

## ASD characteristics in adults

DSM5 Criteria <sup>3</sup> for ASD		Examples of How Criteria May Manifest in Adults	
A. Persistent deficits in social communication and social interaction across multiple contexts. (Diagnosis requires person meets all three criteria.)	1. Deficits in social-emotional reciprocity	Difficulty initiating or sustaining back and forth conversation; tendency to monologue without attending to listener cues; unusual response to greetings or other social conventions.	
	2. Deficits in nonverbal communicative behaviors used for social interaction	Lack of eye contact; difficulty understanding non-verbal communication; unusual tone of voice or body language.	
B. Restricted, repetitive patterns of behavior, interests, or activities. (Diagnosis requires person meets at least two of four criteria.)	3. Deficits in developing, maintaining, and understanding relationships	Challenges adapting behavior to match different social settings such as when interacting with family, friends, authority figures, or strangers; difficulty developing or sustaining friendships; greater than usual need for time alone.	
	1. Stereotyped or repetitive motor movements, use of objects, or speech	Repetitive movements or "stimming" (eg, rocking, flapping, pacing, or spinning for enjoyment or as a coping mechanism); arranging objects in a very precise manner; echolalia; continuously repeating sounds, words, or phrases.	
C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)	2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior	Greater than expected degree of distress with changes in routines or expectations; difficulty transitioning between activities; need to do the same thing in the same way each time; greater than usual reliance on rituals for accomplishing daily tasks.	
	3. Highly restricted, fixated interests that are abnormal in intensity or focus	Intense special interests (eg, looking at spinning objects for hours, learning the detailed schedules of an entire public transportation system, or becoming an expert in seventeenth century art) while having significant difficulty attending to topics outside of one's areas of special interest.	
D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.	4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment	Being hyper- or hypo-sensitive to sounds, lights, smells, or textures; having an abnormally high or low pain threshold; difficulty processing more than one sense at a time (eg, not being able to understand spoken language while looking at someone's face); tendency to become confused or overwhelmed by sensory stimuli; challenges with body awareness or separating different types of sensations.	
		Though characteristics should have been present throughout one's lifetime, a change in circumstances can disrupt coping strategies and make characteristics more pronounced; alternatively, environmental facilitators, supports, and coping strategies may make characteristics less noticeable.	
E. These disturbances are not better explained by intellectual disability or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.		Characteristics lead to difficulty obtaining or sustaining employment, doing basic or instrumental activities of daily living, maintaining social life, or integrating with community. For example, there may be significant mismatch between educational attainment and occupational history.	
		N/A	

Data from American Psychiatric Association. Diagnostic and statistical manual of mental disorders, Fifth edition (DSM-5). Washington, DC: American Psychiatric Association; 2013.

**Table 2**  
Examples of alternative and augmentative communication (AAC) assistive technology

Text		Image	Symbols		Gesture
Unaided (no device)					<ul style="list-style-type: none"><li>American Sign Language</li><li>Body language</li></ul>
Low-tech	<ul style="list-style-type: none"><li>Writing with pencil/paper</li></ul>	<ul style="list-style-type: none"><li>Drawing with pencil/paper</li></ul>	<ul style="list-style-type: none"><li>Braille</li></ul>		
	<ul style="list-style-type: none"><li>Letter board</li></ul>	<ul style="list-style-type: none"><li>Picture board</li><li>Photographs</li><li>Manipulation of physical objects/ models</li></ul>	<ul style="list-style-type: none"><li>Symbolic language like Bliss Symbolics or MinSpeak on a board</li></ul>		
High-tech	<ul style="list-style-type: none"><li>Text-to-speech device (example: DynaVox DynaWrite)</li></ul>	<ul style="list-style-type: none"><li>Picture-based device (example: DynaVox Maestro)</li></ul>	<ul style="list-style-type: none"><li>Symbolic device (example: Dyna-Vox with Bliss Symbolics package)</li></ul>		
	<ul style="list-style-type: none"><li>Text-to-speech software (example: Prolo-quo2Go for iPhone)</li></ul>	<ul style="list-style-type: none"><li>Picture-based software (example: AssistiveWare's LayoutKitchen)</li></ul>	<ul style="list-style-type: none"><li>Symbolic software (example: WinBliss software)</li></ul>		

Many of these devices can also be equipped with alternative interfaces, such as pointers, switches, and eye gaze systems for individuals with limited motor control or coordination. Assistive Ware's Layout Kitchen (Assistive Ware, Amsterdam, The Netherlands); DynaVox DynaWrite (DynaVox Mayer-Johnson, Pittsburgh, PA); DynaVox Maestro (DynaVox Mayer-Johnson, Pittsburgh, PA); DynaVox with Bliss Symbolics package (DynaVox Mayer-Johnson, Pittsburgh, PA); Proloquo2Go for iPhone (Assistive Ware, Amsterdam, The Netherlands); WinBliss software (AnyCom AB, Yngsjö, Sweden).



Potential strategies and accommodations to address autism spectrum disorder (ASD)-related factors that can affect health care

**Table 3**

ASD-Related Factor	Potential Strategies or Accommodations
Heterogeneity of communication skills between and within autistic individuals	<ul style="list-style-type: none"> <li>Obtain information on patient's               <ul style="list-style-type: none"> <li>Ability to understand spoken language.</li> <li>Ability to speak.</li> <li>Ability to read and write.</li> <li>Use of alternative and augmentative communication (AAC).</li> <li>Preferred communication mode.</li> <li>Ability to use the telephone for between-visit communications (and alternatives if telephone is not effective).</li> <li>Communication variability based on environmental factors or stress.</li> </ul> </li> <li>Do not assume that a patient cannot understand health care information or communicate because they cannot speak fluently.</li> <li>Do not assume that a patient with fluid speech or an advanced vocabulary does not have significant communication difficulties.</li> <li>Attempt to use the most effective communication mode, even if it means altering your usual interview style.</li> </ul>
Tendency to take language literally and need for precise language	<ul style="list-style-type: none"> <li>Be very concrete and specific.</li> <li>Avoid expressions and figures of speech.</li> <li>Avoid very broad questions. (Some patients may need only "yes," "no," questions; others may be able to answer open-ended questions if provided with specific instructions or examples.)</li> <li>Show lists of symptoms to choose from.</li> <li>Give examples of the types of things people may experience and have the patient tell you if he or she also experiences them.</li> <li>Remind that it is OK to not know the answers to questions or not to be 100% exact.</li> <li>Give very blunt and concrete examples when discussing your assessment and plan.</li> <li>Direct to detailed information about health conditions and treatment options.</li> </ul>
Atypical nonverbal communication	<ul style="list-style-type: none"> <li>Patient may have difficulty understanding tone of voice, facial expressions, or body language.</li> <li>Patients may inadvertently seem rude because of their atypical body language or facial expressions (potentially in addition to use of very direct language).</li> <li>Do not force patient to make eye contact; it may be uncomfortable or hinder effective communication.</li> </ul>
Slow processing speed	<ul style="list-style-type: none"> <li>Give time to process what has been said or to respond. Check if ready to move on.</li> <li>Give extra time to process sensory input before they respond.</li> <li>Schedule longer appointments.</li> </ul>

ASD-Related Factor	Potential Strategies or Accommodations
	<ul style="list-style-type: none"> <li>• Encourage patients to prepare notes in advance about what they want to discuss. Carefully read any notes that patients bring to the visit. A variety of templates are available to help patients prepare for visits at <a href="http://autismandhealth.org">http://autismandhealth.org</a>.</li> <li>• Write down important information or instructions.</li> <li>• Direct to detailed information or resources about health conditions for review outside of the appointment.</li> <li>• Allow patient to communicate decisions at a later time. It may be possible to see another patient and then return to finish a visit with the original patient, or it may be best to schedule a follow-up visit.</li> </ul>
Increased or decreased sensory sensitivity; difficulty processing multiple stimuli at once.	<ul style="list-style-type: none"> <li>• Use natural light, turn off fluorescent lights, make the lighting dim.</li> <li>• Try to see the patient in a quiet room.</li> <li>• Only have one person talk at a time and try not to talk to the patient while there are other noises.</li> <li>• Avoid unnecessarily touching the patient (for example, to express concern).</li> <li>• Warn the patient before you touch him or her.</li> <li>• Encourage patient or supporters to bring objects to reduce or increase sensory stimuli. Examples may include headphones to block noise or sensory toys or fidgets.</li> </ul>
Repetitive ("stimming") behaviors	<ul style="list-style-type: none"> <li>• Stimming may be an effective coping mechanism, especially during times of stress, such as medical visits. Do not try to dissuade stimming behaviors or assume that a patient is not paying attention because he or she is fidgeting, making repetitive movements, or not looking at you.</li> </ul>
Atypical body awareness, pain, and sensory processing	<ul style="list-style-type: none"> <li>• Consider the possibility that differences in body awareness may be affecting how a patient recognizes or describes a symptom, or how a patient responds to illness.</li> <li>• In some cases, you may need to do additional testing or imaging, as information from the history and physical may be limited.</li> </ul>
Need for consistency	<ul style="list-style-type: none"> <li>• Before a visit, ask staff to:             <ul style="list-style-type: none"> <li>– Let the patient or his or her supporters know what is likely to happen.</li> <li>– Avoid rescheduling appointments and notify as soon as possible of unexpected changes.</li> <li>– Enable the patient to procure pictures of the office and/or staff</li> <li>– When checking in, let the patient know how long the wait is likely to be, and give plenty of warning about delays.</li> </ul> </li> <li>• During a visit:             <ul style="list-style-type: none"> <li>– Make a problem list with the patient, and collaboratively decide what to address.</li> <li>– Explain, in detail, what is likely to happen during the visit.</li> <li>– Write down a list of topics and point out when there is a change of topic.</li> <li>– Show the patient equipment before using it. If possible, do a "trial run" of difficult examinations or procedures.</li> </ul> </li> </ul>
Limited time awareness	<ul style="list-style-type: none"> <li>• Link questions about time to important events in the patient's life.</li> </ul>

ASD-Related Factor	Potential Strategies or Accommodations
	<ul style="list-style-type: none"><li>• Work with the patient to best explain time-based recommendations; for example, help the patient set up an alarm for when to take a pill, or link the act of taking a pill to specific parts of their daily routine.</li></ul>
Visual thinking	<ul style="list-style-type: none"><li>• Offer to use diagrams, pictures, or models with patients who may benefit from them.</li><li>• Create (or have your staff or the patient's supporters create) visual schedules for your recommendations. For example, make a visual schedule for when a patient should take his or her medications.</li></ul>
Difficulties planning, organization, and sequencing	<ul style="list-style-type: none"><li>• Write out detailed step-by-step instructions.</li><li>• Show the patient what you want him or her to do while the patient is still in your office.</li><li>• Have office staff help the patient schedule follow-up visits, referrals, or tests.</li><li>• Show or have someone show the patient how to get to other places in your office or medical center.</li><li>• Have office staff contact the patient or his or her supporters after the visit to make sure that the patient has been able to follow your instructions.</li><li>• Provide worksheets or diaries to keep track of symptoms.</li><li>• Provide detailed information about how to communicate with office staff between visits.</li></ul>

*Adapted from the Academic Autistic Spectrum Partnership Research and Education (AASPIRE) Healthcare Toolkit. Available at: <http://autismandhealth.org/>. Accessed June 23, 2014.*